

# **A I D S TREATMENT N E W S**

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# AIDS Treatment News

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## Statement of Purpose:

*AIDS Treatment News* reports on experimental and standard treatments, especially those available now. We interview physicians, scientists, other health professionals, and persons with AIDS or HIV; we also collect information from meetings and conferences, medical journals, and computer databases. Long-term survivors have usually tried many different treatments, and found combinations that work for them. *AIDS Treatment News* does not recommend particular therapies, but seeks to increase the options available.

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To protect your privacy, we mail first class without mentioning AIDS on the

more than a third of all teenage girls have HIV. But going to school is protective. These are just a few of the facts about HIV and gender that need to be more widely known.

## Prison Health Care: Activist Campaign Targets Hepatitis, HIV Care for

### Prisoners, and Continuity of Care After Release.....

A new activist group wants to force medical practices in prisons to meet national standards for treatment and care, especially for hepatitis C and HIV.

## After the Election.....

It is too early to know exactly how the recent elections will affect people with AIDS. But clearly the community will have to do more to improve and support advocacy for treatment and care, and for policies that work.

## Saving AIDS Conferences Online: Interview with Sister Mary Elizabeth, Founder of AEGiS

by John S. James

AEGiS (<http://www.AEGiS.org/> -- AIDS Education Global Information System) has provided a huge library of AIDS information free to the world for over 12 years. Just one of its projects puts AIDS conference abstracts online, when no one else has done so. Even in today's computer age some of the scientific presentations at major AIDS meetings may have already been lost to history. After the conference ends, people go home and offices close, and often no one takes responsibility to make sure that the abstracts are online -- and that they are available to major databases such as the U.S. National Library of Medicine, so that future researchers can do one search for their topic of interest (instead of having to search dozens of different conferences separately with different

search rules and limitations, which in practice seldom happens).

AEGiS, besides making available AIDS news from sources around the world, has worked with the National Library of Medicine to post missing information on its site, <http://www.AEGiS.org>, and at NLM. On October 22, 2004, *AIDS Treatment News* interviewed its founder and director of operations, Sister Mary Elizabeth.

*AIDS Treatment News*: How long do conferences usually keep scientific or medical abstracts and other conference information online after the meeting ends?

Sister Mary Elizabeth: Our experience here is that conferences could disappear anywhere from six months to three years after being held. It depends on the organization. And many of the conferences never showed up on the Web. So we look around to find people who might have a copy of the abstracts and put them online.

ATN: What is your experience with getting permission to do so?

Mary Elizabeth: Some of the organizations have been extremely cooperative. International Medical Press has given us the file when we asked. Usually it is a flat PDF file, and we go through and extract all the abstracts from it. They have checked back in their records to find some of the older conferences for us and sent them too, with a note giving us permission to archive and distribute them. They have been wonderful to work with.

Others have been less cooperative. With the International AIDS Society, it was hard to get anybody to respond. But then it changed the copyright notice on its Web site, giving permission to reproduce the conferences for non-commercial purposes. That opened the door for us.

And the Retroviruses conference has never responded to any of our letters asking for permission. But these abstracts are available in the National Library of Medicine's AIDSLINE, which we have licensed since the early 90s.

The British HIV Association approached us about carrying their abstracts. These are relatively small conferences, but they put out some very valuable information. They sent us the abstracts of the 10th conference, and we posted those. And when I requested back issues of conferences, they responded almost immediately and sent us the 7th, 8th, and 9th, which we started archiving today.

"ATN: What does AEGiS have that U.S. National Library of Medicine does not?

We have a number of conferences that the National Library of Medicine has not yet added. For example, we have the 8th and 9th European AIDS conference, and the 7th, 8th, 9th, and 10th British HIV Association conferences.

We also added the 4th and 5th International Workshop on Adverse Drug Reactions and Lipodystrophy in HIV. The 6th Lipodystrophy is being loaded this week. Additionally, we have added the 12th and 13th International HIV Drug Resistance Workshops, and the 5th and 6th International Congress Drug Therapy in HIV Infection (Glasgow) conferences. Thomson ACUMED staff are working to get us the 7th conference, scheduled for mid November.

To the best of my knowledge, NLM had not yet incorporated any of these into the NLM Gateway. AEGiS staff is providing them copies of all source files, as well as our finished product, and although I cannot speak for NLM, I believe these meeting abstracts will eventually be incorporated into their database.

I should mention that Lippincott has the copyright on the earlier Glasgow

conferences (International Congress on Drug Therapy in HIV Infection). They gave us permission to post the 5th conference, and Rachel Day recently wrote that she had found a copy of number 4. I'm still negotiating on this one.

ATN: Can our readers help find missing conferences? Maybe someone has a printed copy or a CDROM of an early meeting on their shelves, for a conference that is not now available online anywhere in the world.

Mary Elizabeth: Some of the early conferences did distribute printed books, but nobody to my knowledge has them, not even the National Library of Medicine. And the International AIDS Society told me that they do not have some of their earlier conferences, not even a printed copy in their library. Some of these may be lost forever. Or maybe a reader of this article knows where a printed or CDROM copy of one of these conferences can be found.

We are also still hunting for the Glasgow conferences 1, 2, and 3. Sometimes you see a Google reference to these, because there may be a single abstract online, or a mention in an article. Our goal is to find as many of the missing conferences as we can, and get them into the archive where they are available to the world. [See "Missing Conferences List: Can You Find Any of These?" below.]

If anyone reading this has or knows of a copy (print or electronic) of one of these conferences that we might be able to borrow, please call me at AEGiS, 949-248-5843; our hours are 8 a.m. to 4 p.m. Or you could mail us at AEGiS, 32234 Paseo Adelanto, Suite B, San Juan Capistrano, CA 92675-3622. After we find the material we negotiate with the copyright holder for permission to publish it.

ATN: Also, could you explain the problem with the tables in published conference abstracts?

Mary Elizabeth: If you look at the National Library of Medicine's Pub Med or Gateway databases, when the abstract contains data in a table, often there is a note, "See printed abstract." That works if you have access to the printed abstract, but otherwise you are out of luck. Apparently the NLM software does not handle tables well. We put the tables in, making each abstract a separate file in XHTML format, and people can read the tables on AEGiS.

ATN: Also, explain how other Web sites can link to the abstracts on AEGiS, but often not at the U.S. National Library of Medicine. This hurts the dissemination of scientific information, because online journals or other publication cannot link to abstracts that they reference.

Mary Elizabeth: The NLM Gateway [the database that has most of the AIDS conferences] as currently designed does not give you a URL that you can use to link to the abstract. NLM is trying to resolve this problem.

NLM's Pub Med uses a different search engine, and you are able to link to abstracts. But now most of the conference abstracts are no longer included in Pub Med. They were separated out and put into the Gateway.

ATN: How can people help AEGiS? Can you give readers an idea of the budget?

Mary Elizabeth: The whole AEGiS project runs on a little over \$200,000 per year, and money is tight, so a contribution matters. Tax-deductible contributions can be made by credit card or check. Just click the Donate Now button on any page at <http://www.AEGiS.org>.

Fundraising from our users is difficult because people pay to get on the Internet, so they tend to think everything is free or

paid for it. They don't tend to give much thought to the expense of maintaining a Web site.

AEGiS is run on a budget that is a fraction of similar Web sites. Although AEGiS receives a number of grants to support its operations, user support is required for financial needs not met by the grants. The bottom line is that AEGiS is often stretched to capacity, in both funding and staff. This often results in publication delays, forcing us to make difficult decisions.

ATN: How many records does AEGiS now have online?

Mary Elizabeth: We have somewhat more than 1.1 million records right now -- abstracts, full-text news articles, journal articles from the AIDS organizations like Gay Men's Health Crisis (<http://www.gmhc.org/>); HIV i-Base (<http://www.i-base.info/>) out of the UK, we carry their treatment bulletin; BETA (<http://www.sfaf.org/beta/>); AIDS Weekly ([http://www.newsrx.com/product\\_descriptions/all\\_list.htm](http://www.newsrx.com/product_descriptions/all_list.htm)), which would cost \$1500 a year for a subscription, but they graciously allow us to post two major articles of our choice each week, and permanently archive them, going back to around 1995 now. We get AFP (<http://www.afp.com/english/home/>), which would cost \$75,000 a year; they make it available to us in five languages, English, French, German, Spanish, and Portuguese. Reuters and Associated

Press would each cost \$5,000 a month if AEGiS were paying for them. We have been fortunate to get these in-kind donations.

Some organizations, including RITA (<http://www.centerforaids.org/rita/>), HIV i-Base (<http://www.i-base.info/>), AmfAR (<http://www.amfar.org/>), CATIE (<http://www.catie.ca/e/pubs/>), and of course

AIDS Treatment News (<http://www.aidsnews.org>) were glad to have us carry their material. Some we had to fight with to get, like BETA many years ago. Then the late Tomas Fabrigas became our advocate on the board, and they finally gave us permission, after a big article in the San Francisco Examiner about the battle.

Some of the early issues of CATIE were mimeographed and did not scan very well, so we had to type them in.

ATN: Where could our readers learn about the history of AEGiS?

Mary Elizabeth: They can probably find more history in the newspaper articles that have been written about us over the years, than from our material. Go into the search engine at <http://www.AEGiS.org/> and search for "Sister Mary Elizabeth" (quotes not necessary), and you will get all the articles. There are more than 30 now, all the way back to the time before the Web, when we were a BBS (computer bulletin-board system). You can also find some history in our About AEGiS section.

Our hope has been that archiving some of the old scientific reports, even back from the 1980s on projects that did not pan out, could help future research. Some researcher now may read one of those abstracts or articles and say, "I can see why it failed -- but if they had gone

this other route... " opening a whole new chain of investigation. And maybe even finding a cure.

### **Missing Conferences List -- Can You Find Any of These?**

Here are the major AIDS conferences that, as far as we know, do not have their abstracts available online anywhere in the world, and do not have even a paper copy at the U.S. National Library of Medicine, or at the sponsor or publisher that organized the meeting. Probably most of these collections still exist somewhere, on library, university, company, or personal shelves. Others may already have been lost forever.

- \* International AIDS Conference, numbers 1, 2, 3, and 4.

- \* Conference on Retroviruses and Opportunistic Infections, numbers 1 and 2.

- \* International Conference on Drug Therapies in HIV Infection (Glasgow, Scotland), numbers 1, 3, and 4.

- \* International Workshop on Adverse Drug Reactions and Lipodystrophy in HIV, numbers 2 and 3.

- \* International HIV Drug Resistance Workshop, numbers 1 through 10.

[Note: The last two, the Lipodystrophy and Resistance workshops, are technically supplements of the journal *Antiviral Therapy*. But that does not mean they are available. Even if it is called a supplement, often just enough copies are printed to give to those who attend the meeting, and then they are gone.]

If you know of a copy of any conference on this list that AEGiS might be able to borrow, call Sister Mary Elizabeth at 949-248-5843, 8 a.m. to 4 p.m. weekdays Pacific time. Or you could write her at AEGiS, 32234 Paseo Adelanto, Suite B, San Juan Capistrano, CA 92675-3622.

## **Warning on Two Specific 3-Drug Regimens: Viread + Videx + Either Sustiva or Viramune**

On November 12 the U.S. Food and Drug Administration's AIDS listserve noted a Dear Doctor letter from Bristol-Myers Squibb, warning that the two particular three-drug combinations noted above had shown a high rate of virologic failure in treatment-naïve patients with high viral loads (about half of those patients failed the treatment). The problem seems to be specific to these regimens, as Sustiva has worked with Viread-based regimens, and with Videx-based regimens, in different trials.

The FDA email is available on its archive,  
<http://www.fda.gov/oashi/aids/listserve/listserve2004.html> (you need to scroll down). And this page has the full BMS Dear Doctor letter attached.

### **Comment**

There are now several antiretroviral regimens that failed to control the virus, and were not predicted to fail on the basis of clinical trials, physicians' experience, and known drug interactions. The leading theory seems to be that the bad combinations have a genetic barrier against the virus that is too low. If so, then it may be possible to better predict such failures from existing resistance data -- and perhaps to improve other regimens as well, by avoiding possible weaknesses that are less serious but still important. Has anybody yet brought this information together into a model that works?

## **New Treatment Guidelines**



## Published October 29

A revision to the *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents* was published October 29, 2004. The most current version of this and other U.S. HIV-related guidelines is always available

<http://aidsinfo.nih.gov/guidelines/> -- in either PDF, HTML, or PDA format.

Changes in this revision include when to start antiretroviral treatment, what to start with, discontinuation or interruption of antiretroviral therapy, and special populations: HIV-infected adolescents, injection drug users, hepatitis B/HIV co-infected patients, hepatitis C/HIV co-infected patients, and HIV patient with tuberculosis.

## Retroviruses Conference: Community Deadlines, Nov. 23

The 12th Conference on Retroviruses and Opportunistic Infections, February 22-25, 2005, in Boston, has nine different deadlines, three of them on November 23: Community Educator Program Applications, Community Press Applications, and International Scholarship Applications. Note that some people will need to obtain a scholarship even if they do not need the money, as otherwise they will not be allowed into the conference, which is not open to everyone.

"Community Press" means AIDS newsletters, etc. ("Consumer Press" -- *New York Times*, *Washington Post*, etc. -- has a much later application deadline, but its reporters also must register in advance in order to attend.)

For more information visit <http://www.retroconference.org>. For the deadlines, click 'Dates to Remember'. And for instructions on registering as press, click 'Media Participation'. For instructions for community educators or international scholarship applicants, click 'Travel Grants and Scholarships'.

## World AIDS Day, December 1: Women and Girls

by John S. James

The 2004 World AIDS Day (December 1) will focus on "Women, Girls, HIV & AIDS." Local organizations plan and carry out most World AIDS Day events independently, often working through regional coordinators. This year there is no regional coordinator in the United States, but organizations can find background and many resources at [http://www.unaids.org/wac2004/index\\_en.htm](http://www.unaids.org/wac2004/index_en.htm)

A 23-page *Strategy Note* for the 2004 World AIDS Campaign on women and girls is filled with compelling information that should be more widely known. For example,

"The rate of HIV infection among young people worldwide is growing rapidly -- 67% of newly infected individuals in the developing world are young people aged between 15 and 24 years. The escalating risk is especially evident among young women and girls (15-24 years), who make up 64% of the young people in developing countries living with HIV or AIDS.

"Globally, young women and girls are more susceptible to HIV than men and boys, with studies showing they can be 2.5 times more likely to be HIV-infected as their male counterparts. In sub-Saharan Africa, girls and young women

are twice as likely to be HIV-infected as young men, with up to six times the infection rate of their male peers in parts of the sub-region. In parts of eastern and southern Africa, more than one-third of teenage girls are infected with HIV. This trend is also emerging in some Caribbean countries.

"So far 30 million people have died of AIDS in the two decades since the epidemic began and 40 million more people are currently infected. In poor countries, six million people with HIV/AIDS need antiretroviral treatment immediately, and women and children make up a large proportion of those who need care, treatment and support.

"Women are twice as likely as men to contract HIV from a single act of unprotected sex, but they remain dependent on male cooperation to protect themselves from infection. ..."

"Going to school is protective. Education is one of the key defenses against the spread of HIV and the impact of AIDS and the evidence for this is growing. ..."

"Where sexual violence is widespread, abstention or insisting on condom use is not a realistic option. ... Across the world, between one fifth and a half of all girls and young women report that their first sexual encounter was forced."

Quoted from *World AIDS Campaign 2004: Women, Girls, HIV and AIDS, Strategic Overview and Background Note*, February 2004. available through <http://www.unaids.org/en/events/campaigns/world+aids+campaign+2004.asp>

### **Note: Sexual Violence Research Initiative**

Separately from the 2004 World AIDS Campaign, the World Health Organization is encouraging research on sexual violence and what works to stop

if. A major focus of this effort is HIV. For more information see <http://www.who.int/svri/en/>.

## **Prison Health Care: Activist Campaign Targets Hepatitis, HIV Care for Prisoners, and Continuity of Care After Release**

by Laura McTighe

Access to Health Care for the Incarcerated (a working group of the AIDS Treatment Activists Coalition, ATAC), is fighting for the health care rights of prisoners with hepatitis C and HIV. While many states have adopted HIV and hepatitis C treatment guidelines, prisons often have huge discrepancies between official policy and actual practice of medical care. Many prisons, for example, use restrictions to limit treatment eligibility and avoid the cost of medically necessary care. Prisoners who are able to access medical care are rarely given education about the side effects of treatment, authorization to enable them to form support groups, or exemptions from work requirements, even when their side effects are too severe. When released, prisoners are often sicker than when they entered prison, and have no referrals for medical care, housing, or drug treatment.

Activists are needed to help force medical practices in prison to meet national standards for treatment and care. People can contribute in many ways, including strategy coordination, information sharing, advocacy, and training for allied individuals, organizations, and communities. The working group, including prison activists, health-care activists, ex-